



*RICK, living with hATTR amyloidosis,  
and LYNN, his spouse and caregiver*

## Becoming a caregiver

A guide to caring for a loved one with hereditary ATTR (hATTR) amyloidosis

# The role of a caregiver

When a family member has been diagnosed with hATTR amyloidosis, the range of symptoms that come with the disease may require a loved one to become a caregiver.

Becoming a caregiver is a significant responsibility and can present challenges that require lifestyle changes for you and your loved one.

**We're here to help. This guide provides you with information, tips, and suggestions on how to best support your loved one.**

With the help of your healthcare team and supportive organizations, you can make informed decisions that are best for you and your families.

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*SUE, living with hATTR amyloidosis*



# Understanding hATTR amyloidosis

hATTR amyloidosis is a rare, inherited condition that affects several parts of the body. As a caregiver, it's important for you to be aware of the symptoms of hATTR amyloidosis so you can help keep track of your loved one's condition and communicate effectively with their doctor.

## Many of the symptoms of hATTR amyloidosis can affect a loved one's daily life, including:



**Carpal tunnel syndrome**



**Unintentional weight loss**



**Strange sensations or loss of sensitivity**



**Loss of mobility**



**Severe stomach issues**



**Dizziness upon standing**

This is not a complete list of symptoms that may be experienced in patients with hATTR amyloidosis. Each patient has a different experience and patients may not experience all of these symptoms, or they may not experience them at the same time. Symptoms of hATTR amyloidosis may worsen over time.

Find a more detailed list at [www.hATTRbridge.com](http://www.hATTRbridge.com) or in The Bridge<sup>®</sup> Educational Brochure.

# Tips for caregivers

## Learn about hATTR amyloidosis



By educating yourself about hATTR amyloidosis, you can have more informed conversations with your loved one about the disease and the journey ahead. Knowing about the disease's symptoms and resulting effects can also help you feel more prepared and communicate more effectively with doctors and other healthcare professionals.

## Make a plan



It's important to manage your time to ensure that you and your loved one aren't overwhelmed. Create an organized schedule and routine with your family member that makes time for both of your needs.

## Have an open dialogue



Communication is one of the most important elements of caregiving. Talking with your loved one may help you form a stronger bond, as well as allow you to share insights with your loved one's doctor about their health and emotional well-being. Be open and honest about your state of mind as well. Having a strong support network can help you with your own emotional journey.

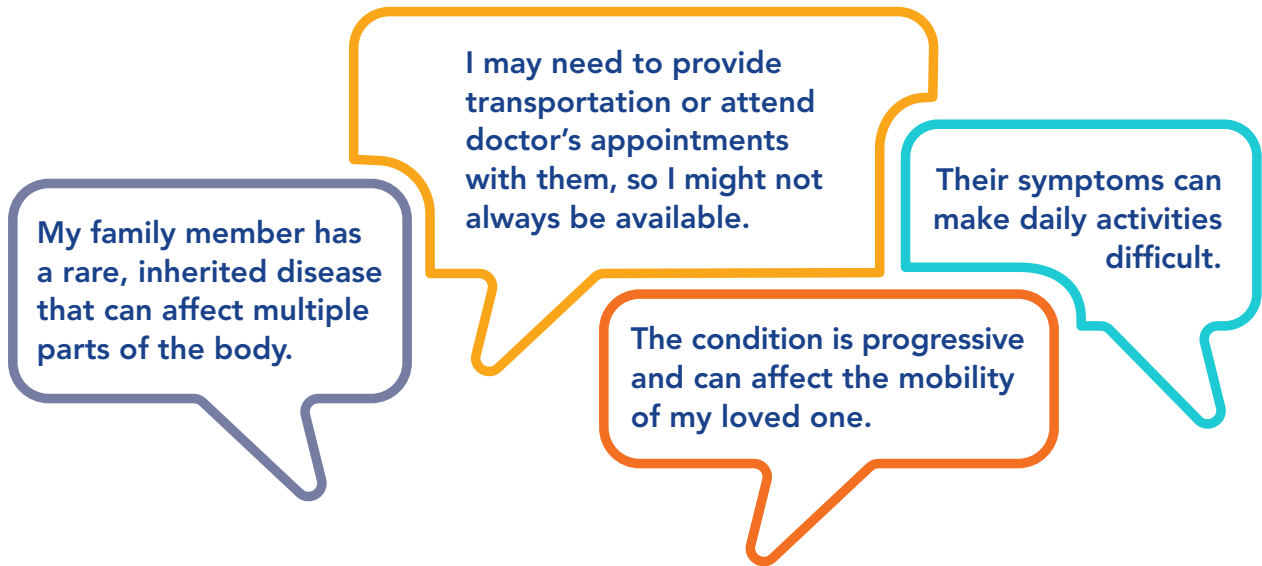
## Keep track of symptoms



Taking note of your loved one's symptoms can make it easier when talking to their doctor about tracking disease progression and about managing the condition.

## Explain your circumstances to others


The responsibility of being a caregiver can sometimes require adjustments to your schedule or routine. Here are some suggestions about how to talk about hATTR amyloidosis and your role as a caregiver:



## Take time to care for yourself



It's important to look out for your own well-being when taking care of others. Be sure to interact socially outside of the caregiving environment and continue to focus on your health with exercise, sleep, and a balanced diet.



I'm blessed that I have a lot of people who support me as a caregiver.

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**LYNN**, caregiver of a loved one living with hATTR amyloidosis

## Seek support

Advocacy and support groups are available nationally and locally to provide you with a network of people who may have similar questions, concerns, and caretaking experiences.

## Sources for additional information and assistance

### **Amyloidosis Foundation**

[www.amyloidosis.org](http://www.amyloidosis.org)

### **Amyloidosis Research Consortium**

[www.arci.org](http://www.arci.org)

### **Amyloidosis Support Groups**

[www.amyloidosisupport.org](http://www.amyloidosisupport.org)

### **The Foundation for Peripheral Neuropathy**

[www.foundationforpn.org](http://www.foundationforpn.org)

### **Global Genes**

[www.globalgenes.org](http://www.globalgenes.org)

### **National Organization for Rare Disorders**

[www.rarediseases.org](http://www.rarediseases.org)



Visit

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